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Withholding or withdrawing life-sustaining treatment from children

In the past 12 months, there have been two significant Australian decisions that have considered the legal right of a competent adult to refuse life-sustaining medical treatment contemporaneously and in advance of the medical situation arising.[1] While there have been no landmark Australian cases on this point, difficult questions regarding the withholding or withdrawing of life-sustaining medical treatment can also arise in relation to children (being those under 18 years old). This editorial considers some of the legal principles that are relevant in such cases.

At the very start of life, parents of very premature neonates or those with severe congenital conditions may, together with treating medical practitioners, face questions over whether to withhold or withdraw life-sustaining treatment during the early stages of life.[2] For others, these questions may arise later in life where parents reject life-sustaining medical treatment for their children due to personal beliefs or religious reasons.[3] Where the child in question is mature, there are questions regarding the extent to which the child may make their own decision regarding life-sustaining treatment.

1) General Principles

Generally speaking, if a child lacks capacity, a decision regarding treatment will ordinarily fall to those with parental responsibility. If a child satisfies the test for *Gillick*-competence,[4] that child may consent to treatment but a refusal of consent may be overridden by the courts. The same general principles apply when considering withholding or withdrawal of life-sustaining treatment. The most important principle at law continues to be upholding the 'best interests' of the child.

Where disputes do arise, the courts with jurisdiction include the Queensland Supreme Court exercising *parens patriae* jurisdiction and the Family Court exercising federal jurisdiction under the *Family Law Act 1975* (Cth).

2) Queensland Legislation

[1] *Brightwater Care Group v Rossiter* [2009] WASC 229 and *Hunter and New England Area Health Service v A* [2009] NSWSC 761 respectively.

[2] See for example, *Re B (A Child) (Medical Treatment)* [2008] EWHC 1996 (Fam); [2009] 1 FLR 1264; *Re K (a child) (withdrawal of treatment)* [2006] EWHC 1007 (Fam); [2006] 2 FLR 883; *Re Wyatt (a child) (medical treatment: continuation of order)* [2005] EWCA Civ 1181; [2005] 1 WLR 3995.

[3] For example, cases exist of parents who are Jehovah's Witnesses refusing to consent to blood transfusions for their children and of parents refusing consent to chemotherapy for their child in preference for alternative remedies (discussed below).

[4] A child will be considered 'Gillick-competent' if he or she has sufficient intelligence and maturity to understand the nature and consequences of the particular medical treatment: *Secretary, Department of Health and Community Services v JMB and SMB* (1992) 175 CLR 218, 237-8, referring to the test originally established in *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, 189.

In some circumstances, where *withholding* treatment from a child is at issue, legislation may prevent a refusal of consent from operating. In particular, legislation exists that governs the situation where any child under 18 years[5] requires a blood transfusion and there is a refusal to provide consent to that procedure.

In Queensland, blood transfusions can be administered to children in the face of refusal of consent (by a parent or another with lawful authority), or where such consent has not been obtained.[6] The legislation requires that two medical practitioners must be of the opinion that a blood transfusion is necessary to 'preserve the life of the child'. The section deems blood transfusions carried out in accordance with the legislation to be treated as if they have been carried out with the consent of the parent or the person with authority to consent.[7]

Where there are concerns that in a specific case the legislation may not apply, an application can be made to a court to authorise the treatment in the child's best interests.[8]

3) Children without capacity

a) Disputes at the start of life

Often decisions regarding withholding or withdrawing life-sustaining treatment need to be made at the start of an infant's life – especially where an infant is very premature or suffers from severe congenital conditions.[9] These infants may have very little, or no, prospect of recovery or improved quality of life, but still suffer pain and are kept alive through life-sustaining medical treatment.

However, in making decisions to withhold or withdraw such treatment, Australia lacks judicial guidance. In practice, a decision about whether to withhold or withdraw treatment from such young infants will be made by parents in consultation with medical practitioners. If the withholding or withdrawal of treatment is in the best interests of the child and all parties agree, parents may lawfully refuse such treatment and there will be no reason to approach the courts.[10] Professional guidelines exist that identify circumstances when it might be appropriate to withhold or withdraw treatment from infant, in particular those with congenital conditions or who are severely premature.[11]

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[5] In the *Transplantation and Anatomy Act 1979* (Qld), the term 'child' is not defined. However, the *Acts Interpretation Act 1954* (Qld), s 36 defines child as an individual under the age of 18 years.
[6] *Transplantation and Anatomy Act 1979* (Qld), s 20.
[7] *Transplantation and Anatomy Act 1979* (Qld), s 20(2).
[8] See for example, see *Re R* (2000) 2 Qd R 328.
[9] A report from a hospital in Victoria found that more than 75% of deaths recorded in the neonatal intensive care unit were as a consequence of the withdrawal or withholding of potentially life-saving treatment: D J Wilkinson et al, 'Death in the neonatal intensive care unit: changing patterns of end of life care over two decades' (2006) 91 *Archives of Disease in Childhood - Fetal and Neonatal Edition* F268.
[10] See *Re K (a child) (withdrawal of treatment)* [2006] EWHC 1007 (Fam); [2006] 2 FLR 883, [42]. Note that the best interests standard will not be satisfied at law if parents and practitioners agree to withhold treatment from a disabled child (e.g. a child with Down's syndrome) that would otherwise be likely to survive and live a healthy life if the treatment were provided, see *Re B (a minor) (wardship: medical treatment)* [1981] 1 WLR 1421; *R v Arthur* (1981) 12 BMLR 1.
[11] See for example The Royal Australasian College of Physicians, Paediatrics & Child Health Division, *Decision-Making at the End of Life in Infants, Children and Adolescents – A Policy of the Paediatrics*

However, should parents and practitioners disagree – which happens most often when practitioners want to withhold or withdraw treatment but parents wish treatment to continue – the courts may be called on to determine the issue.[12] The best interests of the child remains the appropriate legal test. To determine what must be considered in this context, we must look to UK decisions.

The clearest guidance comes from the case of *Re Wyatt* [2005] EWCA Civ 1181; [2005] 1 WLR 3995 where an application was made to the court to authorise that a young infant not receive intubation and ventilation in the event that she suffered a collapsed lung. In that case the Court outlined the following factors that a court would need to take into account in determining what would be in the best interests of a child in such a case:[13]

> The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient...There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable...The term "best interest" encompasses medical, emotional, and all other welfare issues...The court must conduct a balancing exercise in which all the relevant factors are weighed... and a helpful way of undertaking this exercise is to draw up a balance sheet.[14]

The determination of best interests in such a case may also take into account whether the child's quality of life is judged to be 'intolerable', but this will not be the sole factor.[15] It was emphasised that the outcome in each case will be 'highly fact specific' and it will be up to the judge to strike a balance between benefit and harm.[16]

b) Parental Refusal

& Child Health Division of The Royal Australian College of Physicians (2008). For similar international guidelines see, Royal College of Paediatrics and Child Health, *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice*, (2nd ed, 2004); Committee on Bioethics, 'Guidelines on Forgoing Life-Sustaining Medical Treatment' (1994) 93 *Pediatrics* 532; Nuffield Council on Bioethics, *Critical care decisions in fetal and neonatal medicine: ethical issues*, (2006). See also Kei Lui et al, "Perinatal care at the borderlines of viability: a consensus statement based on a NSW and ACT consensus workshop" (2006) 185 Medical Journal of Australia 495.

[12] This is recognised in Australian guidelines: The Royal Australasian College of Physicians, Paediatrics & Child Health Division, *Decision-Making at the End of Life in Infants, Children and Adolescents – A Policy of the Paediatrics & Child Health Division of The Royal Australian College of Physicians* (2008) p 16.

[13] *Re Wyatt (a child) (medical treatment: continuation or order)* [2005] EWCA Civ 1181; [2005] 1 WLR 3995, [87].

[14] For an example where the court adopted the 'balance sheet' approach see *An NHS Trust v MB* [2006] EWHC 507 (Fam); [2006] 2 FLR 319, [60]-[81].

[15] *Re Wyatt (a child) (medical treatment: continuation or order)* [2005] EWCA Civ 1181; [2005] 1 WLR 3995, [91].

[16] *Re Wyatt (a child) (medical treatment: continuation or order)* [2005] EWCA Civ 1181; [2005] 1 WLR 3995, [88]-[89].

Where the issue is refusal of life-sustaining treatment by a parent, domestic case law does exist. These cases generally relate to situations where parents reject life-sustaining medical treatment due to personal beliefs or religious reasons.

As discussed above, legislation in Queensland allows for blood transfusions to be given to children in limited circumstances. If the legislation does not cover a specific situation, courts have shown a willingness to authorise the giving of blood products to a child.[17]

Australian courts have also authorised other types of life-sustaining medical treatment to be provided to young children where parents have refused consent to such treatment. For example, in *Re Heather* [2003] NSWSC 532 the parents of an eleven year old girl with a malignant tumour of the ovary consistently refused consent for their child to undergo chemotherapy. The parents wished to explore alternative methods of treating her cancer. Medical practitioners were of the opinion that failure to commence chemotherapy could jeopardise the child's life. Orders were then sought and granted by the New South Wales Supreme Court for the Department of Community Services to authorise procedures that were, on medical advice, considered to be in the interests of the child.[18] Similarly, in the *Re Michael* cases (*Re Michael* (1994) 17 Fam LR 584 and *Re Michael (No 2)* (1994) 17 Fam LR 27), applications were made to the Family Court because parents refused consent to a surgical procedure aimed at relieving the symptoms of a congenital heart condition suffered by their son. Orders were originally made authorising the procedure although, ultimately, the parents provided undertakings to the Family Court that they would ensure that their child received appropriate medical and/or surgical treatment.

However, a court will not always automatically side with medical practitioners in such applications; the guiding principle is always what is in the best interests of the child as determined by the facts of each case. Factors that may be relevant to a determination of best interests include the medical evidence presented, the options for treatment, the risks involved and prospects of success, and the likely pain and discomfort to be experienced by the child.

For example, in the UK case of *Re T* [1997] 1 WLR 242, although medical opinion unanimously favoured that a child with a life threatening liver defect be given a liver transplant, the Court of Appeal found that the course of action in the best interests of the child was for the transplant not to occur, as favoured by the parents. The parents had previously witnessed the pain and distress suffered by their son following an earlier unsuccessful operation and were concerned about how the surgery and subsequent treatment would affect their son. In addition, if the transplant was authorised, there was the risk of imposing an unwanted situation upon the mother in circumstances where the child's recovery depended on the parent's commitment to that treatment and any further necessary treatment. The child's welfare, in this circumstance, was highly dependent on the parents.

[17] See n 8.
[18] [2003] NSWSC 532, [20], [52].

4) Children who have capacity

a) Can they refuse?

Where our concern is children who have capacity (i.e. are *Gillick*-competent), the main issue that arises is whether such children can refuse life-sustaining medical treatment. Often the children in question will have suffered from a terminal illness for a long period of time and may have great insight into their condition; alternatively, mature children may hold strong religious beliefs that limit the treatment they are willing to accept.

At common law, the position in Australia appears similar to that in the UK: even if a child satisfies the test for *Gillick*-competence, the child's refusal of consent to life-sustaining treatment can be overridden by the courts where treatment is considered to be in the best interests of the child.[19] For example, in the case of *Minister for Health v AS* (2004) 33 Fam LR 223, the Supreme Court of Western Australia – while acknowledging that 15 year old 'L' was *Gillick*-competent – authorised the administration of a blood transfusion if certain circumstances arose. In that case 'L' was a practicing Jehovah's Witness who refused consent to blood products.

Despite this, courts have emphasised that overriding a decision of a *Gillick*-competent or maturing child is not to be done lightly and that the court should take into account the views of the child.[20]

In practice, guidelines from the Royal Australasian College of Physicians suggest that some children's ability to competently participate should be recognised, with it being possible for a child to be 'respected as the main decision-maker'.[21] It suggests that those over 16 years old should be able to express their preferences about end of life care and be part of the decision-making process, including place and situation of their death.[22]

While some commentators are critical that *Gillick*-competent children – who have the legal right to consent to treatment – are not conversely able to refuse life-sustaining treatment, it nonetheless seems that the law is not yet ready to relinquish the principle of 'best interests' in relation to all children.

[19] *Minister for Health v AS* (2004) 33 Fam LR 223, [20]. This approach has been endorsed by some legal commentators (e.g. New South Wales Law Reform Commission, *Young People and Consent to Health Care*, Report 119 (2008) [4.48]-[4.50]; J K Mason and G T Laurie, *Mason & McCall Smith's Law and Medical Ethics* (7th ed, OUP, 2006) [10.52]), but also criticised (e.g. Ian Kennedy and Andrew Grubb, *Medical Law* (3rd ed, Butterworths, 2000) pp 985-989; Lynn Hagger, *The Child as Vulnerable Patient: Protection and Empowerment* (Ashgate, 2009) pp 34-38).
[20] See comments in *Minister for Health v AS* (2004) 33 Fam LR 223, [23]; *Royal Alexandra Hospital for Children v J* (2005) 33 Fam LR 448, [50]; *Re W* [1993] Fam 64, 88, 93.
[21] The Royal Australasian College of Physicians, Paediatrics & Child Health Division, n 12, p 7.
[22] The Royal Australasian College of Physicians, Paediatrics & Child Health Division, n 12, p 25.